

CURRENT STATE OF LITERATURE RELATED TO THE EUTHANASIA PRACTICES OF MINORS

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ABSTRACT. Euthanasia of minors is a medical procedure regulated and implemented in Belgium and Nederland. As all Euthanasia practices it is a topic very debated, especially in the field of medical ethics. This paper aim is to identify the literature published on this topic and to delineate the main perspectives of these practices. We collected articles published between 1st of January 2014 and 1st July 2018, treating about practices of euthanasia as a protocol for minors. 73 articles were selected from a total of 292 publications. We were looking to identify, in the same time, the context of the ethical debate on the topic and possible solutions or alternative to these practices.

Key Words: *Ethics, Minors' Euthanasia, End-of-life Decisions Making*

REZUMAT. Stadiul actual al publicațiilor relative la practicile eutanasiei la minori. Eutanasia pentru minori este o procedură medicală reglementată și pusă în aplicare în Belgia și în Olanda. Ca toate practicile eutanasiei este un subiect foarte dezbătut, în special în domeniul eticii medicale. Scopul acestui articol este de a identifica literatura publicată pe acest subiect și de a delimita principalele perspective ale acestor practici. Am colectat articole publicate între 1 ianuarie 2014 și 1 iulie 2018, care tratează practicile eutanasiei ca protocol pentru minori. Au fost selectate 73 de articole dintr-un total de 292 de publicații. Am căutat să identificăm, în același timp, contextul dezbaterii etice pe această temă și soluții posibile sau alternative la aceste practici.

Cuvinte cheie: *etică, eutanasia la minori, deciziile finalului de viață*

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Introduction

Child death is a very sensitive topic and the debate around the world on children end-of-life issues is quite taboo. People do not talk about death, generally speaking, and children's death is somehow against nature, that's why it is very hard to find a good answer to this question. The problem is a society issue and not only a medical practice problem.

Some countries adopted legal regulations on Euthanasia for minors: Netherland in 2002 and Belgium in 2014. We have investigated the ethical reflection behind these practices and the decision to introduce euthanasia as a new protocol for minor's end-of-life care.

As the Hippocrates Oath is one of the important parts in the formation of a medical doctor ("I will use treatment to help the sick according to my ability and judgment, but never with a view to injury and wrong-doing. Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course"), the essential questions are the following: Can Euthanasia be considered part of a medical protocol? And do physicians review their own role, professions, and status?

Methods

The bibliographic search was done in two steps by: 1) using combinations of keywords and "MeSh terms" in the PubMed database and 2) selection on inclusion criteria.

The keywords and MeSh terms used are:

"Ethics / moral", "euthanasia / assisted suicide", "end of life", "legislation / law / rights", "pediatric / pediatrics / children / child", in All Fields.

The languages used to explore the bibliography were: English, French, Romanian.

Table 1. Code MeSh

Ethics + euthanasia + pediatrics + legislation + end of life	(("morals"[MeSH Terms] OR "morals"[All Fields] OR "moral"[All Fields] OR "ethic"[All Fields] OR "ethics"[MeSH Terms]) AND ("suicide, assisted"[MeSH Terms] OR ("suicide"[All Fields] AND "assisted"[All Fields]) OR "assisted suicide"[All Fields] OR ("assisted"[All Fields] AND "suicide"[All Fields]) OR "euthanasia"[MeSH Terms] OR "euthanasia"[All Fields]) AND ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "pediatrics"[MeSH Terms] OR "pediatrics"[All Fields] OR "pediatric"[All Fields]) AND ("legislation"[Publication Type] OR "legislation as topic"[MeSH Terms] OR "legislation"[All Fields] OR "law"[All Fields] OR "right"[All Fields]) AND end[All Fields] AND ("life"[MeSH Terms] OR "life"[All Fields])) AND ("2014/01/01"[PDAT] : "2018/07/01"[PDAT])
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Ethics + euthanasia + pediatrics + legislation	(("morals"[MeSH Terms] OR "morals"[All Fields] OR "moral"[All Fields] OR "ethic"[All Fields] OR "ethics"[MeSH Terms]) AND ("suicide, assisted"[MeSH Terms] OR ("suicide"[All Fields] AND "assisted"[All Fields]) OR "assisted suicide"[All Fields] OR ("assisted"[All Fields] AND "suicide"[All Fields]) OR "euthanasia"[MeSH Terms] OR "euthanasia"[All Fields]) AND ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "pediatrics"[MeSH Terms] OR "pediatrics"[All Fields] OR "pediatric"[All Fields]) AND ("legislation"[Publication Type] OR "legislation as topic"[MeSH Terms] OR "legislation"[All Fields] OR "law"[All Fields] OR "right"[All Fields])) AND ("2014/01/01"[PDAT] : "2018/07/01"[PDAT])
Ethics + euthanasia + pediatrics	(("morals"[MeSH Terms] OR "morals"[All Fields] OR "moral"[All Fields] OR "ethic"[All Fields] OR "ethics"[MeSH Terms]) AND ("suicide, assisted"[MeSH Terms] OR ("suicide"[All Fields] AND "assisted"[All Fields]) OR "assisted suicide"[All Fields] OR ("assisted"[All Fields] AND "suicide"[All Fields]) OR "euthanasia"[MeSH Terms] OR "euthanasia"[All Fields]) AND ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "pediatrics"[MeSH Terms] OR "pediatrics"[All Fields] OR "pediatric"[All Fields])) AND ("2014/01/01"[PDAT] : "2018/07/01"[PDAT])
Ethics+ end of life + pediatrics	(("morals"[MeSH Terms] OR "morals"[All Fields] OR "moral"[All Fields] OR "ethic"[All Fields] OR "ethics"[MeSH Terms]) AND ("end of life"[All Fields] OR "end-of-life"[All Fields]) AND ("child"[MeSH Terms] OR "child"[All Fields] OR "children"[All Fields] OR "pediatrics"[MeSH Terms] OR "pediatrics"[All Fields] OR "pediatric"[All Fields])) AND ("2014/01/01"[PDAT] : "2018/07/01"[PDAT])

Table 1. list the codes used for each search and combination in the PubMed database.

To stay close to the subject the keywords and MeSh terms "ethic / moral" and "pediatric / pediatrics / children / child" were used in each combination to establish a selection criterion appropriate to our purpose.

The combinations are listed in **Table 2**.

The exploratory search followed two steps:

a) The criteria for the selection in the PubMed:

- The date of publication: 1/1/2014 to 1/7/2018
- The search box: All Fields

From a total of 1957 papers found, 292 have been published in between 1st January 2014 and 1st July 2018. After analyzing the title and the abstract, 73 articles, 25% were relevant to our subject.

Papers published after 1st July 2018 were not been included in our study.

b) The exploration of the documents was done by identifying:

- The titles, their relevance to the care of children in the end of life and ethical reflections raised by the topic
- The authors and the geographical origin of the publication

Inclusion criteria are:

- The date of publication: 1st January 2014 to 1st July 2018
- Relevance for the subject.

The bibliographic research focused on the ethical reflections related to the Euthanasia for minors and perspectives in the end-of-life care of minors.

Results

Table 2. Number of different pre or post-selection results

Key-word combination	Total results N	Total result between 2014-2018 N	Selections	
			N	%*
Ethic + euthanasia + pediatric + legislation + end of life	39	11	9	82%
Ethic + euthanasia + pediatric + legislation	492	37	11	30%
Ethic + euthanasia + pediatric	1052	78	11	14%
Ethic + end of life + pediatric	374	166	42	25,3%
	1957	292	73	25%

**the result in % define the total of results concerned between 2014 and 2015*

From 73 publications selected (**Table 3**) 27 of them, 37% (2; 5; 8; 11; 14; 15; 17-22; 27; 31; 47; 49; 51; 52; 54; 55; 61; 63; 65-68; 70) are related to euthanasia of minors, 46 articles, 63% (1; 4; 10; 16; 23-26; 28; 34; 35-46; 50; 53; 56-60; 62; 64; 69; 71-73) present topics related to the end of life of minors. 11 articles, 15% (3; 7; 9; 12; 13; 29-33; 48) treat the legislation on the Euthanasia of minors or legislation related to the end of life of minors.

Table 3. Concordance of keywords and MeSh terms with the selected articles

Ethic/moral	73	100%
Euthanasia/assisted suicide	27	37%
Pediatric/pediatrics/children/child	73	100%
Legislation/law/right	11	15%
End of life	46	63%

The keywords “ethics / moral”, “pediatric / pediatrics / children / child” were used in each combination, all 73 papers, 100% articles are about minors’ ethical issues and end-of-life.

Table 4 present a stratification by publication date for the 73 selected articles, 57 (78%) (2-9; 11-20; 25-31; 34; 36-52; 60-73) were published before 2017, 16 (22%) (1; 10; 21-24; 32; 33; 35; 53-5) were published after this date from 1st January 2017 to 1st July 2018.

Most of the articles were published in 2014, 25 articles (34%) of the total number.

Table 4. Papers/Year

Year	Number of papers	%
2014	25	34%
2015	16	22%
2016	16	22%
2017	9	12%
2018	7	10%
Total	73	100%

Table 5 illustrate the stratification by origin and affiliations of authors. 21 items (29%) (2; 6; 8; 11; 15; 18; 25; 27; 29; 32; 34; 37; 42; 46; 50; 54; 58; 62; 64; 68; 71) of papers are published by authors from United States, 9 (12%) (14; 24; 35; 36; 41; 51; 52; 55; 63;) from Canada and 8 articles (11%) (4; 7; 10; 12; 22; 30; 39; 45) from Netherlands. Authors from France (3, 9, 31, 48,) and the United Kingdom (1; 21; 26; 44) have published 4 papers, (5,5% articles each) and Belgium 3 articles (4%) (16;19;65). 18 articles have been published by authors from different countries.

Table 5. Number and % of selected articles by publication origin

UNITED STATES	21	29%
CANADA	9	12%
NETHERLAND	8	11%
FRANCE	4	5,5%
UNITED KINGDOM	4	5,5%
GERMANY	3	4%
BELGIUM	3	4%
SPAIN	1	1,5%
SWEDEN	1	1,5%
NORWAY	1	1,5%
OTHERS	18	24,5%
Total	73	100%

Table 6 indicate the compatibility proportion of keywords and MeSh terms by country of authors. We note that 75% of selected articles from the Netherlands (6) and 100% from Belgium (3) contain MeSh keywords or words "euthanasia / assisted suicide". For France and the United Kingdom, the results are also high, 50% (2) and 75% (3) respectively.

Selected articles from the United States and Canada containing the keywords and MeSh terms "End of life" have the highest rate 69% (16) for the US and 67% (6) for Canada.

For keywords and MeSh terms "legislation / law / right", the results are 14.3% (3) for the articles published from the United States, 11% (1) for Canada, 25% (2) for articles from the Netherlands, 25% (1) from France, 0% (0) correlation found for the United Kingdom and 33% (1) for Belgium.

Table 6. The compatibility ratio of keywords and MeSh terms by country of publication

	Euthanasia/ assisted suicide		End of life		legislation/law/ right	
	n	%	n	%	N	%
USA	5	31	16	69	3	14.3
CANADA	3	33	6	67	1	11
NETHERLAND	6	75	2	25	2	25
FRANCE	2	50	2	50	1	25
UNITED KINGDOM	3	75	1	25	0	0
BELGIUM	3	100	0	0	1	33

Discussion

The first observation is that the number of publications has decreased over the years, 2014 being the year when 25 articles were published, in 2017 and 2018 there have been published only 9 and 7 papers. The explanation could be that in 2014 Belgium has extended the law on Euthanasia to children, the legislation was implemented, and authors studied and analyzed with pro and cons this initiative and the possibility to be adopted in other countries (Great Britain, France). This is the reason which justifies the enthusiasm on this topic with philosophical and ethical reflection on the subject.

But also, we can suspect many ideas and approaches have been advanced so far and practitioners need time to reflect how to figure out new perspective and clarity on the subject, and the reason that explains the decline in the number of publications over the last two years.

The most of part of authors who treated this topic have affiliations in the United States, maybe because the debate on Euthanasia practices is known and very hot in the North American context.

If we focus on European authors, we noticed that authors are not necessarily from countries where Euthanasia for minors have been regulated. The Netherlands certainly have an acceptable presumed quota who put this country in the first rank in Europe and the third in the world, but authors from Belgium, the pioneers in regulation Euthanasia for minors have not been very interested on this subject, maybe even because they should try to understand better the real consequences of this legal act. Certainly, Netherland have few decades of time to reflect about this subject instead of Belgium. Netherland actually has experimented many issues with assisted suicide and Euthanasia: people are simply administered lethal substances without any given explicit consent, and other issues and errors were observed (van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, et al. End-of-life practices in the Netherlands under the *Euthanasia Act*. *N Engl J Med*. 2007; 356:1957-65. doi: 10.1056/NEJMsa071143.)

One of the important things is to protect the children and to guarantee their autonomy, to protect health professionals who may suffer moral discomfort, but above all to protect society from certain drifts that are contrary to the life.

The most of part of articles are related to the reflection on Euthanasia and the end of life, maybe because for the society, generally speaking, this is a hot topic and it is necessary to mature the subject by relying it on the current societal experiences and reactions.

The decrease in publications over the past two years may be a sign of the society's and practitioners questioning on developments that have been made, in particular, in terms of legislation, the lack of adequate protocols, and the lack of acceptable solutions and alternatives.

There is selection bias in our study, because even if the keywords used allow an exhaustive search on the subject, they do not allow to search all existing articles in the field. Also, we can notice the existence of a classification bias, because even if we made a search in [All fields] as well as in the MeSh terms, the search was not carried out in the whole article.

Conclusion

The results of our study tend to make us understand that after a very advanced step a status quo is installed due to a lack of response from our society as well as the establishment of legislative tools for the practice on field.

The lack of publication in the last two years compared to those before has dropped, maybe because both medical doctors and public opinion accepted the new framework behind the law.

The lack of ethical training of practitioners and the economic issues related to the health support are also valid causes that raised these new realities.

It would therefore be wise to promote ethics, within the medical profession but also in society in order to give people deep understanding and perspectives on the contemporary issues related to the life and death.

We think that a systematic review with a larger sample and a deeper methodology on the research texts should be done, in order to identify the main reflections and approaches of the topic.

In the end, to the question if the decision to include euthanasia in treatment protocols medically is relevant, the answer is that it still does not solve the problem of suffering, it just allows people to avoid real and deep confrontation and to ignore it.

BIBLIOGRAPHY

1. Brouwer M, Maeckelberghe E, DE Weerd W, Verhagen E. Quality of Living and Dying: Pediatric Palliative Care and End-of-Life Decisions in the Netherlands. *Camb Q Healthc Ethics*. 2018 Jul; 27(3):376-384.
2. Hanson SS. Pediatric Euthanasia and Palliative Care Can Work Together. *Am J Hosp Palliat Care*. 2016 Jun; 33(5):421-4.
3. Raus K. The Extension of Belgium's Euthanasia Law to Include Competent Minors. *J Bioeth Inq*. 2016 Jun; 13(2):305-15.
4. ten Cate K, van de Vathorst S, Onwuteaka-Philipsen BD, van der Heide A. End-of-life decisions for children under 1 year of age in the Netherlands decreased frequency of administration of drugs to deliberately hasten death. *Med Ethics*. 2015 Oct; 41(10): 795-8.
5. Koper JF, Bos AF, Janvier A, Verhagen AA. Dutch neonatologists have adopted a more interventionist approach to neonatal care. *Acta Paediatr*. 2015 Sep; 104(9):888-93.
6. Bovens L. Child euthanasia: should we just not talk about it? *J Med Ethics*. 2015 Aug; 41(8):630-4.
7. Eduard Verhagen AA. Neonatal euthanasia: lessons from the Groningen Protocol. *Semin Fetal Neonatal Med*. 2014 Oct; 19(5):296-9.
8. Morrison W, Kang T. Judging the quality of mercy: drawing a line between palliation and euthanasia. *Pediatrics*. 2014 Feb; 133 Suppl 1:S31-6.
9. De Saint Blanquat L, Cremer R, Elie C, Lesage F, Dupic L, Hubert P; pour le Groupe francophone de réanimation et urgences pédiatriques. (GFRUP). [French law related to patient's rights and end of life: pediatric intensive care unit's health professionals' opinions]. *Arch Pediatr*. 2014 Jan; 21(1):34-43.

10. Bolt EE, Flens EQ, Pasman HR, Willems D, Onwuteaka-Philipsen BD. Physician-assisted dying for children is conceivable for most Dutch paediatricians, irrespective of the patient's age or competence to decide. *Acta Paediatr.* 2017 Apr; 106(4):668-675.
11. Kaczor C. Against euthanasia for children: a response to Bovens. *J Med Ethics.* 2016 Jan; 42(1):57-8.
12. ten Cate K, van de Vathorst S. Dutch pediatricians' views on the use of neuromuscular blockers for dying neonates: a qualitative study. *J Perinatol.* 2015 Jul; 35(7):497-502.
13. González-Melado FJ, Di Pietro ML. [The Best Interest of the Child in Neonatology: Is It Best for the Child?]. *Cuad Bioet.* 2015 May Aug; 26(87):201-22.
14. Schuklenk U. Physicians can justifiably euthanize certain severely impaired neonates. *J Thorac Cardiovasc Surg.* 2015 Feb; 149(2):535-7.
15. Sade RM. Can a physician ever justifiably euthanize a severely disabled neonate? *J Thorac Cardiovasc Surg.* 2015 Feb; 149(2):532.
16. Friedel M. [Palliative care in pediatrics, ethics and relations with the patient]. *Soins Pediatr Pueric.* 2014 Nov-Dec; (281):42-6.
17. Voultos P, Chatzinikolaou F. Involuntary euthanasia of severely ill newborns: is the Groningen Protocol really dangerous? *Hippokratia.* 2014 Jul-Sep; 18(3):193-203.
18. Siegel AM, Sisti DA, Caplan AL. Pediatric euthanasia in Belgium: disturbing developments. *JAMA.* 2014 May 21; 311(19):1963-4.
19. Dan B, Fonteyne C, de Cléty SC. Self-requested euthanasia for children in Belgium. *Lancet.* 2014 Feb 22; 383(9918):671-2.
20. Beca JP, Leiva A. [Could infant euthanasia be ever acceptable?]. *Rev Chil Pediatr.* 2014 Oct; 85(5):608-12.
21. Keeling G. The sensitivity argument against child euthanasia. *J Med Ethics.* 2018 Feb; 44(2):143-144.
22. Brouwer M, Kaczor C, Battin MP, Maeckelberghe E, Lantos JD, Verhagen E. Should Pediatric Euthanasia be Legalized? *Pediatrics.* 2018 Feb; 141(2).
23. Blikshavn T, Husum TL, Magelssen M. Four Reasons Why Assisted Dying Should Not Be Offered for Depression. *J Bioeth Inq.* 2017 Mar; 14(1):151-157.
24. Pennaforte T, Moussa A, Janvier A. [Speaking about life and death in neonatology: How can communication with families be optimized?]. *Arch Pediatr.* 2017 Feb; 24(2):146-154.
25. Rapoport A, Morrison W. No child is an island: ethical considerations in end-of-life care for children and their families. *Curr Opin Support Palliat Care.* 2016 Sep; 10(3):196-200.
26. Liao L, Chan D. Physician-hastened death in young children: Getting to underlying assumptions. *Paediatr Child Health.* 2016 May; 21(4):181-2.
27. Carter BS. Why Palliative Care for Children is Preferable to Euthanasia. *Am J Hosp Palliat Care.* 2016 Feb; 33(1):5-7.
28. Clément de Cléty S, Friedel M, Verhagen AA, Lantos JD, Carter BS. Please Do Whatever It Takes to End Our Daughter's Suffering! *Pediatrics.* 2016 Jan; 137(1).

29. Leeuwenburgh-Pronk WG, Miller-Smith L, Forman V, Lantos JD, Tibboel D, Buysse C. Are we allowed to discontinue medical treatment in this child? *Pediatrics*. 2015 Mar; 135(3):545-9.
30. Willems DL, Verhagen AA, van Wijlick E; Committee End-of-Life Decisions in Severely Ill Newborns of Royal Dutch Medical Association. Infants' best interests in end-of-life care for newborns. *Pediatrics*. 2014 Oct; 134(4):e1163-8.
31. Béranger A, Boize P, Viillard ML. [The practices of withdrawing artificial nutrition and hydration in the neonatal intensive care unit: a preliminary study]. *Arch Pediatr*. 2014 Feb; 21(2):170-6.
32. Kim MJ, Lee JH, Lee HD. Recent Changes in End-of-Life Decisions for Newborns in a Korean Hospital. *Am J Hosp Palliat Care*. 2018 Apr; 35(4):574-578.
33. Mishra S, Mukhopadhyay K, Tiwari S, Bangal R, Yadav BS, Sachdeva A, Kumar V. End-of-Life Care: Consensus Statement by Indian Academy of Pediatrics. *Indian Pediatr*. 2017 Oct 15; 54(10):851-859.
34. Suttle ML, Jenkins TL, Tamburro RF. End-of-Life and Bereavement Care in Pediatric Intensive Care Units. *Pediatr Clin North Am*. 2017 Oct; 64(5):1167-1183.
35. Janvier A, Farlow B, Verhagen E, Barrington K. End-of-life decisions for fragile neonates: navigating between opinion and evidence-based medicine. *Arch Dis Child Fetal Neonatal Ed*. 2017 Mar; 102(2):F96-F97.
36. Lam V, Kain N, Joynt C, van Manen MA. A descriptive report of end-of-life care practices occurring in two neonatal intensive care units. *Palliat Med*. 2016 Dec; 30(10):971-978.
37. Thieleman KJ, Wallace C, Cimino AN, Rueda HA. Exhaust All Measures: Ethical Issues in Pediatric End-of-Life Care. *J Soc Work End Life Palliat Care*. 2016 Jul-Sep; 12(3):289-306.
38. Grosek S, Orazem M, Kanic M, Vidmar G, Groselj U. Attitudes of Slovene paediatricians to end-of-life care. *J Paediatr Child Health*. 2016 Mar; 52(3):278-83.
39. Zaal-Schuller IH, de Vos MA, Ewals FV, van Goudoever JB, Willems DL. End-of-life decision-making for children with severe developmental disabilities: The parental perspective. *Res Dev Disabil*. 2016 Feb-Mar; 49-50:235-46.
40. Chan LC, Cheung HM, Poon TC, Ma TP, Lam HS, Ng PC. End-of-life decision-making for newborns: a 12-year experience in Hong Kong. *Arch Dis Child Fetal Neonatal Ed*. 2016 Jan; 101(1):F37-42.
41. Rahimzadeh V, Bartlett G, Longo C, Crimi L, Macdonald ME, Jabado N, Ells C. Promoting an ethic of engagement in pediatric palliative care research. *BMC Palliat Care*. 2015 Oct 16; 14:50.
42. Sanchez Varela AM, Johnson LM, Kane JR, Kasow KA, Quintana Y, Coan A, Yuan Y, Barfield R, Church C, Hester M, Baker JN. Ethical decision making about end-of-life care issues by pediatric oncologists in economically diverse settings. *J Pediatr Hematol Oncol*. 2015 May; 37(4):257-63.
43. Xafis V, Wilkinson D, Sullivan J. What information do parents need when facing end-of-life decisions for their child? A meta-synthesis of parental feedback. *BMC Palliat Care*. 2015 Apr 30; 14:19.
44. Fowler A, Freiburger D, Moonan M. Palliative and end-of-life care in pediatric solid organ transplantation. *Pediatr Transplant*. 2015 Feb; 19(1):11-7.

45. de Vos MA, Bos AP, Plötz FB, van Heerde M, de Graaff BM, Tates K, Truog RD, Willems DL. Talking with parents about end-of-life decisions for their children. *Pediatrics*. 2015 Feb; 135(2):e465-76.
46. Bateman LB, Clair JM. Physician Religion and End-of-Life Pediatric Care: A Qualitative Examination of Physicians' Perspectives. *Narrat Inq Bioeth*. 2015 Winter; 5(3):251-69.
47. Weber M. [Decisions at the end of life of children and adolescents pose particular legal problems. Our expert illuminates the legal status. Judges can deny custody in certain cases]. *Pflege Z*. 2014 Nov; 67(11):686-8.
48. Lefeuvre C, Viillard ML, Schell M. [Pediatric palliative care: a national survey of French pediatric residents' knowledge, education, and clinical experience]. *Arch Pediatr*. 2014 Aug; 21(8):834-44.
49. Rydvall A, Juth N, Sandlund M, Domellöf M, Lynøe N. To treat or not to treat a newborn child with severe brain damage? A cross-sectional study of physicians' and the general population's perceptions of intentions. *Med Health Care Philos*. 2014 Feb; 17(1):81-8.
50. Jones BL, Contro N, Koch KD. The duty of the physician to care for the family in pediatric palliative care: context, communication, and caring. *Pediatrics*. 2014 Feb; 133 Suppl 1:S8-15.
51. Janvier A, Barrington K, Farlow B. Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology. *Semin Perinatol*. 2014 Feb; 38(1):38-46.
52. Dupont-Thibodeau A, Barrington KJ, Farlow B, Janvier A. End-of-life decisions for extremely low-gestational-age infants: why simple rules for complicated decisions should be avoided. *Semin Perinatol*. 2014 Feb; 38(1):31-7.
53. Rost, M., Acheson, E., Kühne, T. et al. Palliative care in Swiss pediatric oncology settings: a retrospective analysis of medical records. *Support Care Cancer* (2018) 26: 2707.
54. Santoro JD, Bennett M. Ethics of End of Life Decisions in Pediatrics: A Narrative Review of the Roles of Caregivers, Shared Decision-Making, and Patient Centered Values. *Behav Sci* (Basel). 2018 Apr 26; 8(5).
55. Kirsch R, Munson D. Ethical and end of life considerations for neonates requiring ECMO support. *Semin Perinatol*. 2018 Mar; 42(2):129-137.
56. Hoell JI, Warfsmann J, Gagnon G, Trocan L, Balzer S, Oommen PT, Borkhardt A, Janßen G, Kuhlen M. Palliative care for children with a yet undiagnosed syndrome. *Eur J Pediatr*. 2017 Oct; 176(10):1319-1327.
57. Silberberg AA, Gallo JE. Ethical dilemmas associated with clinicians' decisions about treatment in critically ill infants born in Córdoba, Argentina. *J Child Health Care*. 2017 Mar; 21(1):121-126.
58. Sweeney CD. A DAISY Nurse: Moral Distress and End-of-Life Decisions in the Pediatric Setting. *J Nurs Adm*. 2017 Feb; 47(2):82-84.
59. Delany C, Xafis V, Gillam L, Hughson JA, Hynson J, Wilkinson D. A good resource for parents, but will clinicians use it?: Evaluation of a resource for paediatric end-of-life decision making. *BMC Palliat Care*. 2017 Jan 25; 16(1):12.

60. Downing J, Kiman R, Boucher S, Nkosi B, Steel B, Marston C, Lascar E, Marston J. Children's palliative care now! Highlights from the second ICPCN conference on children's palliative care, 18-21 May 2016, Buenos Aires, Argentina. *E cancer medical science*. 2016 Aug 23; 10:667.
61. Xafis V, Watkins A, Wilkinson D. Death talk: Basic linguistic rules and communication in perinatal and paediatric end-of-life discussions. *Patient Educ Couns*. 2016 Apr; 99(4):555-561.
62. Carter BS. End of life decisions for newborns: an ethical and compassionate process? *Arch Dis Child Fetal Neonatal Ed*. 2016 Mar; 101(2):F92-3.
63. Hellmann J, Knighton R, Lee SK, Shah PS; Canadian Neonatal Network End of Life Study Group. Neonatal deaths: prospective exploration of the causes and process of end-of-life decisions. *Arch Dis Child Fetal Neonatal Ed*. 2016 Mar; 101(2):F102-7.
64. Hendricks-Ferguson VL, Kane JR, Pradhan KR, Shih CS, Gauvain KM, Baker JN, Haase JE. Evaluation of Physician and Nurse Dyad Training Procedures to Deliver a Palliative and End-of-Life Communication Intervention to Parents of Children with a Brain Tumor. *J Pediatr Oncol Nurs*. 2015 Sep-Oct; 32(5):337-47.
65. Dan B. End-of-life management in children. *Dev Med Child Neurol*. 2015 Aug; 57(8):688.
66. Kadivar M, Mosayebi Z, Asghari F, Zarrini P. Ethical challenges in the neonatal intensive care units: perceptions of physicians and nurses; an Iranian experience. *J Med Ethics Hist Med*. 2015 Feb 4; 8:1. eCollection 2015.
67. Isaacs D. Ethics of paediatric end-of-life decision making and consent for publication. *J Med Ethics*. 2015 Feb; 41(2):201-2.
68. Sellers DE, Dawson R, Cohen-Bearak A, Solomond MZ, Truog RD. Measuring the quality of dying and death in the pediatric intensive care setting: the clinician PICU-QODD. *J Pain Symptom Manage*. 2015 Jan; 49(1):66-78.
69. Morales VG. [Limitation of the therapeutic effort in pediatric intensive care]. *Rev Chil Pediatr*. 2015 Jan-Feb; 86(1):56-60.
70. Valdez-Martinez E, Noyes J, Bedolla M. When to stop? Decision making when children's cancer treatment is no longer curative: a mixed-method systematic review. *BMC Pediatr*. 2014 May 13; 14:124.
71. Jankowski JB. Professional boundary issues in pediatric palliative care. *Am J Hosp Palliat Care*. 2014 Mar; 31(2):161-5.
72. Kiman R, Doumic L. Perinatal palliative care: a developing specialty. *Int J Palliat Nurs*. 2014 Mar; 20(3):143-8.
73. Ringholz F, Devins M, McNally P. Managing end stage lung disease in children. *Paediatr Respir Rev*. 2014 Mar; 15(1):75-80.